1	Supporting Public Health's Role in Addressing Unmet Needs in Serious Illness and	
2	at the End of Life: Innovative Models of Palliative and End-of-Life Care	
3		
4	Abstract:	
5	This proposed policy statement addresses the public health problem of growing suffering	
6	and illness burden among older adults who are faced with advanced life-limiting and	
7	chronic illness as they age. The policy calls for public health prevention and intervention	
8	strategies to improve gerontological health and promote active aging and well-being	
9	through innovative models of palliative and end-of-life care. Focusing on the patient and	
10	the family as the unit of care, palliative approaches to care target advance care planning	
11	improved communication and care coordination, prevention and relief of pain and	
12	suffering, and multidimensional assessment and care responses. Recommendations for	
13	externally directed support include building the public health infrastructure through	
14	palliative care workforce development, increasing access to palliative care services,	
15	public education programs and campaigns about the right to palliative care and pain	
16	management, and funding of research to support expansion of palliative care initiatives	
17	and interprofessional training.	
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20	Related policy:	
21	APHA policy statement 2005-9: Supporting Public Health's Role in Addressing Unmet	
22	Needs at the End of Life1 relates to the identified public health problem.	
23		
24	Rationale for consideration:	
25	The proposed policy updates and replaces the existing APHA policy statement 2005-9:	
26	Supporting Public Health's Role in Addressing Unmet Needs at the End of Life. The	
27	proposed policy addresses a policy gap identified by the Joint Policy Committee and	
28	Staff for the current year in gerontological health and active aging as well as policy gaps	
29	in new palliative systems of care and related public heath infrastructures. The proposed	
30	policy statement addresses these gaps by promoting palliative care education, training,	

1 services and research funding in order to embed palliative care in gerontological care 2 systems and responses.

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Problem Statement:

6 The American Public Health Association has supported a major role for federal, state, 7 and local government health agencies in assuring health care is maximally responsive to 8 the public's needs. A public need which has been inadequately addressed is the 9 prevention of many of the adverse consequences of living with advanced life-limiting and 10 chronic terminal illness, and interventions during the course of illness. Persons with 11 cancer and other non-cancer chronic terminal illnesses such as advanced heart failure and 12 late stage dementia suffer physically, emotionally and socially across all stages of 13 illness, 2,3 and frequently do not have conversations with their health professionals about their goals of care, values and preferences. Palliative care is a therapeutic model of care 14 15 that defines the patient and family as the unit of care and aims to improve communication 16 between patients and their health professionals, to promote health literacy through 17 evidence-based practice tools such as patient decision aids, and to increase participation 18 in shared informed decision making. Palliative approaches to care also seek to manage care transitions more effectively through better care coordination, to optimize quality of 20 life, to manage distressing symptoms and reduce pain levels, and to prevent and relieve 21 suffering among seriously ill patients. 4-6 Hospice care, a form or subset of palliative 22 care, is a comprehensive interdisciplinary care program that provides pain and symptom 23 management as well as psychosocial, emotional, and spiritual support services to 24 patients. 7,8 There has been rapid growth in hospice over the past decades – in 2010, over 25 40% of Americans who died were receiving hospice. 9 In addition, families and caregivers of persons with serious or chronic terminal illnesses often experience 27 increased morbidity or premature mortality resulting from the stress and strains 28 associated with a loved one's terminal decline, as well as stress experienced serving in 29 the role of surrogate decision maker when a loved one no longer has capacity. 10-13 30 Health care and social service providers, public health professionals, and state and local health departments [together with their collaborators (e.g., aging networks, state units on

1	aging, and others)] have a role in preventing and relieving this suffering,14 and thus, in		
2	assuring maximum responsiveness to public needs.1 The promotion of quality of life for		
3	seriously ill and dying individuals and their family members, caregivers and survivors is		
4	integral to the achievement of the Healthy People 2020 goal of increasing the quality ar		
5	years of healthy life,15 and to promoting death with dignity.16		
6			
7	Federal health reform (Patient Protection and Affordable Care Act of 2009)		
8	implementation is also driving the rapid integration of primary care, mental health car		
9	and palliative care. Innovative models of care delivery are evolving that include fully		
10	integrated systems that provide person-centered care through medical homes, and embe		
11	palliative care in the community through interdisciplinary collaboration among		
12	physicians, nurse practitioners, and social workers as well as other health professions.17		
13			
14	The critical importance of public health practice and public health research to priorities in		
15	hospice, palliative and end-of-life care demand the urgent attention of public health		
16	professionals and advocates in the other health professions. Advancing public health		
17	research will inform both practice and public policy decision making in meeting the		
18	challenges of improved health and health care, efficiency, and public health ethics.		
19			
20	Suffering and illness burden and death are universal experiences affecting millions of		
21	Americans annually in the United States;18 and three-quarters of all deaths are of persons		
22	65 years of age and older, with the vast majority being from chronic disease, 19-21 and		
23	dying persons and their loved ones frequently experience preventable negative		
24	consequences of serious and terminal illness and decline;4 and that this suffering is		
25	amenable to population-based interventions.22,23 Palliative care (including hospice		
26	care—a specialized form of palliative care) is underutilized in the United States,5,6,24		
27	even though its goal is to provide "effective management of pain and other distressing		
28	symptoms, while incorporating psychosocial and spiritual care according to		
29	patient/family needs, values, beliefs and culture(s),"25 and even though hospice care has		
30	been shown to be associated with greater family satisfaction and fewer patient/family		
31	unmet needs3,26,27 and with improvements in pain assessment and management.28,29		

Proposed Recommendations Statement:

With the aging of the population, the proportion of deaths associated with chronic terminal illness will increase, resulting in increased needs for a trained gerontological workforce in generalist-level palliative care, and important opportunities to develop effective interventions for improving advance health care planning including the evidence-based Physician Orders for life-Sustaining Treatment Paradigm 30 and palliative and end-of-life care.31,32,

As reported by the Institute of Medicine (IOM) in its comprehensive report on pain, pain care and pain management and its blueprint for a public health response to pain, improved pain care is a public health priority for older adults who are higher risk for inadequate pain care assessment and treatment.14

The IOM has also issued a report on public health and the law and more specifically infrastructural, interventional and intersectoral laws as well as other legal tools that are recommended in addressing public health priorities for the aging population.33

The Association of State and Territorial Chronic Disease Program Directors (CDD) and the Centers for Disease Control and Prevention (CDC) facilitated a systematic process which considered input and ideas from nationally prominent stakeholders with expertise in end of life, public health, aging, and cancer and resulted in priority recommendations aimed at assisting State Health Departments in identifying the role of public health in addressing end-of-life issues,23 recommendations congruent with and complementary to existing APHA policies and priorities.1,16,34 APHA continues to support the intent of the CDC and CDD to identify a chronic disease point person within state health departments to coordinate/liaison end-of-life activities with relevant issues in aging and serious illness; collect, analyze and share data about end of life through state surveys; educate the public about the availability of hospice and palliative care and the importance of advance care planning; and eliminate financial barriers to third party payment for early and comprehensive hospice and palliative care, priority recommendations which many states are moving towards implementing.31,35-37

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1	Opposing Arguments/Evidence:	
2	There is some evidence of overuse of hospice care, a form of palliative care, in nursing	
3	homes. The Office of the Inspector General of Health and Humans Services is	
4	scrutinizing hospice lengths of stay in the nursing home industry, primarily among for-	
5	profit entities. 38 While there is variation in the use of hospice, regulators may not fully	
6	understand and take account of the complexity of nursing home populations, their illne	
7	and suffering burden and high prevalence of multimorbidity. Consideration also needs	
8	be given to the ethical implications of resource allocations and their potential	
9	disproportionate impact upon vulnerable subgroups of older adults such as minority	
10	women who are living in resource-poor nursing homes and may be denied access to	
11	hospice care.	
12		
13	Alternative Strategies:	
14	There is a widespread recognition that there is a serious shortage of trained	
15	gerontological professionals who are equipped to meet the needs of the growing older	
16	adult population in the US. This shortage is a public health crisis. Efforts have been	
17	initiated by various professional associations and foundations such as the John A.	
18	Hartford Foundation to develop competencies in nursing and social work, for example.	
19	Gwyther and colleagues (2005) have mapped out competencies in palliative social work.	
20	39	
21		
22	Action Steps:	
23	APHA endorses and supports the following action steps to improve gerontological health,	
24	active aging and well-being:	
25	1) State health departments should take an active public health role in addressing	
26	palliative and end-of-life issues and unmet needs among seriously ill older adults,	
27	including advocating for patient rights, and honoring of patients' self-determination and	
28	participation in shared informed decision making about their end-of-life decisions.	
29	2) State government and State health departments should promote effective pain care and	
30	pain management for older adults in serious illness and at the end of life including	

removal of barriers to the appropriate use of opioids.

Submitted by February 15, 2012

1	3) State health departments, health providers and public and private agencies should	
2	cooperate and collaborate in:	
3	i) promotion of advance care planning including the provision of information and	
4	counseling about health care proxies, palliative and end-of-life options and	
5	Physician Orders for Life-Sustaining Treatment (POLST) for end-of-life decisions	
6	through interprofessional education, research and practice by and among qualified	
7	health care providers and professionals, academic institutions, government	
8	entities, and community coalitions;	
9	ii) promotion of the use of hospice and palliative care through education about its	
10	availability and benefits among health care providers, public health professionals	
11	and government entities; and	
12	iii) improved care coordination across the continuum of care to reduce	
13	unnecessary and harmful care transitions that result in adverse outcomes for	
14	seriously ill older adults.	
15	6) Federal and state governments should make funding available to support professional	
16	education and training to develop a gerontological workforce in generalist-level palliative	
17	care, and to implement new laws and palliative systems of care across all health care	
18	settings and in the community; in addition, make funding available for essential public	
19	health research to inform practice and public policy decision making in gerontological	
20	health and aging; and finally, assure that health reform initiatives at the federal and state	
21	levels are funded to permit innovations in palliative care delivery such as medical homes	
22	to eliminate health disparities among the sickest and most vulnerable older adults.	
23		
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1	Appendix A
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5	2/14/12
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11	
12	To APHA Staff:
13	
14	
15	This letter serves as confirmation that proposed policy statement "Supporting Public
16	Health's Role in Addressing Unmet Needs in Serious Illness and at the End of Life
17	Innovative Models of Palliative and End-of-Life Care" was submitted by Mary Beth
18	Morrissey on behalf of Aging and Public Health Section.
19	
20	Signed,
21	Lené Levy Storms
22	Chair, Aging and Public Health Section
23	
24	
25	
26	
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Appendix B. Author Disclosure Statement

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3 A separate form must be completed for each author listed on the proposed policy

4 statement.

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Conflicts of interest (competing interests) include facts known to a participant in the

7 policy statement development process that if revealed later, would make a reasonable

reader feel misled or deceived (or an author or reviewer feel defensive). Conflicts of

interest may influence the judgment of authors and reviewers; these conflicts often are

not immediately apparent to others or to the reviewer. They may be personal,

11 commercial, political, academic, or financial.

12

13 Financial interests may include employment, research funding (received or pending),

stock or share ownership, patents, payment for lectures or travel, consultancies,

nonfinancial support, or any fiduciary interest in the company. The perception or

appearance of a conflict of interest, without regard to substance, alone creates conflict,

because trust is eroded among all participants.

18

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17

All such interests (or their absence) must be declared in writing by authors upon

submission of the proposed policy statement. If any are declared, they will be included

21 with the policy statement proposal during the review process. If there is doubt about

whether a circumstance represents a conflict, it should be disclosed.

23

Required Disclosure: During the past 12 months have you, or your spouse or partner			
had a personal, commercial, political, academic, or financial interest or relationship that			
might potentially bias and/or impact content of the proposed policy statement: Yes			
□ X No			
If yes, please list the interest or relationship:			
• /•			
This policy statement was developed with guidance from Bruce Jennings of the Ethics			
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Guidance was also provided by members of the policy committee of the Aging and			
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D2-13